Does the subjective quality of life of children with Specific Learning Disabilities (SpLD) agree with their parents' proxy reports?

V. Rotsika,[1] M. Coccossis[2], M. Vlassopoulos[1], E. Papaeleftheriou[1], K. Sakellariou[1], D.C. Anagnostopoulos[1], A. Kokkevi[2], S. Skevington[3]

1. Lecturer of Psychology, Community Mental Health Center, A' Psychiatric Clinic, Medical School, University of Athens, 14 Delou Street, Kaissariani, Athens, Greece, T.K. 16121.
2. Assist. Professor of Clinical Psychology, A' Psychiatric Clinic, Medical School, University of Athens, 72, Vas. Sophias Av., Athens, Greece, T.K.11528
3. Lecturer of Language and Communication Pathology, Community Mental Health Center, A' Psychiatric Clinic, Medical School, University of Athens, 14 Delou Street, Kaissariani, Athens, Greece, T.K. 16121
4. School Psychologist, Research assistant, Community Mental Health Center, A' Psychiatric Clinic, Medical School, University of Athens, 14 Delou Street, Kaissariani, Athens, Greece, T.K. 16121
5. Psychologist, Community Mental Health Center, A' Psychiatric Clinic, Medical School, University of Athens, 14 Delou Street, Kaissariani, Athens, Greece, T.K. 16121.
6. Assist. Professor of Child and Adolescent Psychiatry, Community Mental Health Center, A' Psychiatric Clinic, Medical School, University of Athens, 14 Delou Street, Kaissariani, Athens, Greece, T.K. 16121.
7. Professor of Clinical Psychology and Epidemiology, A' Psychiatric Clinic, Medical School, University of Athens, 72, Vas. Sophias Av., Athens, Greece, T.K. 11528.
8. Professor of Health Psychology, WHO Centre for the Study of Quality of Life and Department of Psychology, University of Bath, Bath, UK.

Corresponding Author: V. Rotsika, email: krotsika@med.uoa.gr
Tel. +302107601000, +302108082906
Fax. +302108018958

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Abstract

Purpose. The aim of the present study was to investigate agreement between child-parent proxy reports on quality of life (QoL) in children with Specific Learning Disabilities (SpLD) and in a control group of typically developing children.

Methods. 116 children aged 8-14 years with SpLD and 312 same age typically developing children with their parents (one or both) respectively, completed the child and parent versions of the KINDL^R questionnaire. Values were analyzed with ANOVA and Intra Class Correlation coefficient (ICC).

Results. Significant mean differences were found between children with SpLD and their mother's proxy ratings. So, mothers reported significantly lower scores in the dimension of *everyday functioning in school*, but significantly higher scores regarding the child's *physical* and *emotional well being*. For typically developing children, significant differences between children and parents' proxy ratings were found in *physical well-being* and *self esteem* with both parents reporting higher scores. Concerning ICC, correlations were few and low in the SpLD group but more robust in the typically developing child-parent proxy ratings with values ranging from 0.22 to 0.46.

Conclusion. In the case of SpLD, the child's problem area, which is reflected in the KINDL^R dimension of *everyday functioning in school*, seems to be an issue of controversial value that may be differentially perceived by children and their mothers. Further, it can be argued that as mothers seemed to perceive in a more negative way the child's QoL at school, they were at the same time attempting to counterbalance their reactions by overestimating the child's *physical* and *emotional* well-being. Besides differences, there is a tendency -even low- for mothers and children with SpLD to converge towards similar perceptions regarding the child's *physical and emotional well being* and *satisfaction with friends* that is showing some rather common understanding of the child's overall well being and his/her relationships with peers. In the control group, agreement between children and parents seems to be more even and evident. Proxy assessments in children with SpLD and their parents may be useful for planning targeted support interventions for these families.

Key words: Quality of life, Proxy measurement, Specific Learning Disabilities, Typically developing children, Child-parent QoL agreement

Abbreviations
QoL Quality of Life
SpLD Specific Learning Disabilities
ADHD Attention Deficit Hyperkinetic Disorder
ICC Intra Class Correlations coefficients

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Introduction

In contemporary child healthcare, assessment of quality of life (QoL) in children with physical or mental illness has been gaining importance with more attention being given to the psychosocial well-being of children with chronic disease, as well as to their parents and siblings. The 1948 declaration of the World Health Organization (WHO) is considered to be a fundamental statement indicating that *health is not just an absence of illness and disability, but signifies physical, psychological and social well-being* [1]. Within this context, health and QoL are increasingly addressed as interrelated concepts in paediatric research and practice, so that outcomes of therapeutic interventions equally concern young patients' and their families' physical and mental health. Similarly, parental proxy QoL measurements are of outmost importance, since parents' views about their children's health and well-being can provide motives for parents to seek help or treatment for their children [2].

Despite these benefits, there are questions as to whether parents' views and perceptions about their children's QoL could be taken as a valid substitute for children's own perspectives. Also, whether parent-child QoL reports would agree, which QoL dimensions would be reported as similar or different, but also whether parent-child proxy versions would assess the same concepts or whether instruments would work in parallel.

In general, results concerning parent-child QoL agreement are mixed or controversial depending on the instruments used, the QoL dimensions measured [3], the cultural context wherein the study was conducted [4], or the population investigated, as in healthy versus ill children [2]. For example, regarding healthy children, Jozefiak et al. [5]

reported that there was moderate or high agreement between parents regarding the child's Qol in the KINDL questionnaire (r=0.54) and the ILC inventory (r=0.61). For depressed children, a lower correlation was found between mother-proxy reports (0.20) than in the respective of healthy children (0.31), indicating greater differences in QoL proxy-measurement in clinical child-mother dyads [6].

Regarding parent-child agreement in healthy versus clinical groups of children, Upton et al. [2] indicated that "parents of children in a non-clinical sample tended to report higher child health-related quality of life scores than children themselves, while parents of children with health conditions tended to underestimate child HRQL" (p.895). Similar findings were reported in children with physical or mental illness, including depressed children [6], children with ADHD [7, 8] and adolescents with type 1 diabetes [9]. Also, in children with various psychiatric disorders, parent-child correlations were moderate (0.38 to 0.51) [10], ranging in depressed children from 0.07 to 0.53 [6], while in ADHD children agreement was good (ICC 0.59-0.75) for a number of QoL dimensions [8, 11].

Parent-child QoL agreement has been stronger in certain QoL areas, as for example in concrete aspects, such as health status, namely being well or sick. Thus, agreement regarding the child's physical health has been typically high [4, 8, 12-14], but high agreement has been also reported for the psychosocial aspects of QoL [11, 13, 15, 16].

A qualitative analysis of differences between children and parents' views has shown that both parties of the dyad may interpret the questions in the same way however they tend to answer differently [17]. Specifically, children may choose extreme options and base their answers on a single example while parents may judge their experiences in

a holistic way. Such differences are considered to be connected to the child's stage of cognitive development.

Regarding QoL agreement in children with SpLD and their parents, there has been a shortage of relevant studies investigating differences and similarities with appropriate proxy tools. For example, in a study of parental ratings of Qol of children with SpLD [18], parents in Bombai indicated poorer QoL for their children compared to parents of American children. Accordingly, poorer ratings were reported in 9 out of 12 QoL domains: *family activities, emotional impact on parents, social limitations as a result of physical health, social limitation as a result of emotional-behavioral problems, physical functioning, general health perceptions, time impact on parents, general behavior and mental health*. In a different study, Greek children with SpLD compared to healthy children, reported poorer *emotional well-being*, lower *self-esteem* and deficits in their *relationships* with *family* and *friends* [19].

The purpose of the present study was to investigate parent-proxy QoL agreement in children with SpLD and in typically developing and same aged children and their parents respectively. Previous evidence has shown that in clinical parent-proxy dyads, parents tended to report lower child QoL than children themselves [2, 6, 8, 10]. Also, it has been argued that agreement depends not so much on the QoL-domain per se, but rather *on the clinical relevance of the domain to a given disease* [2]. In the present study, it was hypothesized that parents of children with SpLD would report lower ratings in respect to the QoL dimension which is relevant to the child's problem, so parents would rate their children's *school functioning* lower than children themselves. Investigating parent-child QoL agreement with the use of reliable proxy tools and methodologies could lead to new evidence-based outcomes.

Method

Participants

A cohort of 428 children with one or both parents participated in this study. Inclusion criteria specified that participating children should be between 8 - 14 years old, native language speakers, free from any major health problem, physical or psychiatric. All recruited children were of normal IQ attending mainstream schools. Children and their parents were grouped into two groups:

Group A: 116 children were diagnosed with SpLD (72 boys, 44 girls, mean age 10.67 years, SD = 1.99), and their parents (N=116): 17 fathers, (mean age 42.7 years, SD = 3.11) and 99 mothers (mean age = 41.43 years, SD = 4.58). Because of the low number of fathers participating in the study, the statistical analysis presented concerns only the mother-proxy reports.

Children with SpLD were consecutive referrals for specialized testing in 2 out of the 11 diagnostic facilities offering child-adolescent health services in the area. The participating Mental Health Centers were situated in middle and low socio-economic districts of the city of Athens (population 5 million) [20]. According to Madianos report "the area's sociodemographic characteristics are similar to those of the other boroughs of greater Athens" (p.315) [21].

Children were diagnosed for SpLD by a multidisciplinary team composed of a psychologist, a child psychiatrist and an educational specialist. Diagnosis included ICD-10 criteria (F 81.0 and F 81.1) and IQ assessment with the use of WISC-III. The time interval between consecutive cases to be assessed was 2-3 days approximately, while the participating cases represented 84% of the total number of children diagnosed with SpLD for the time interval of the study. Immigrant children and ages below 8 and above 14 were excluded. A very low percentage of refusals were observed.

Group B: 312 typically developing school children of same age were recruited as a comparison group (153 boys, 159 girls, mean age 11.00 years, SD=1.99), and a total of 499 parents (one or both parents): 30 fathers alone, 95 mothers alone, and 187 cases of both parents. Fathers' mean age was 45.03 years, (SD = 5.07) and mothers' 41.43 years (SD = 4.95). Typically developing children constituted a convenience sample from public schools of the same districts and were similar in terms of age, gender and educational grade.

Measures

Sociodemographic information: Sociodemographic data specified the child's age and gender, and parents' age, gender, years of education, marital status and occupation.

Proxy measurements: Two parallel forms of the QoL questionnaire were used, one of which has been designed for children and the other for parents. Both child- parent proxy forms assess six QoL dimensions.

Self-reported child QoL was assessed using the Greek version of the KINDL^{R} questionnaire [22, 23], a self-report instrument developed specifically to assess QoL in children and adolescents. It consists of 24-Likert scale items constituting six dimensions: *physical well-being*, *emotional well-being*, *self-esteem, relationship with family, with friends* and *everyday functioning in school*. Higher scores in each dimension indicate better QoL. The questionnaire is available in three age-specific versions (4-7, 8-12 and 13-16 years old). The two oldest age versions were used in this study: Kid-KINDL ^{R} Questionnaire /8-12 years and Kiddo-KINDL ^{R} Questionnaire/13-16 years [22]. Translation from the German KINDL ^{R} was conducted by two independent translators and with the contribution of bilingual individuals and one of the authors below, a third form was produced on the basis of consensus, which was back-translated by an

independent translator so that the final pilot form to be tested [23]. The relevant version of the questionnaire can be found in: www. kindl.org

Parent proxy report was used to assess the child's QoL, with the relevant adult language version of the parent KINDL ^{R} questionnaire [22, 23, 24], and specifically the form Kid & Kiddo-KINDL /8-16 years [22]. The parent version contains also six dimensions corresponding to the child's version and both are considered parallel forms. Parental versions of KINDL ^{R} can be found in the same site as above.

Procedure:

Group A (children with SpLD): After securing parental written consent for participation in the study, child and parent questionnaires were completed while visiting the Mental Health Centre, where assessment of the child's learning difficulties was to take place. Parent-child proxy reports were completed simultaneously but in separate rooms.

Group B (typically developing children): Parent questionnaires were sent home via schools, together with a written consent form. Children who returned this form and the parental questionnaire were then able to complete the child version at school. A researcher was present during administration assisting children and informing them about the purpose of the study.

Approval of the study was granted by the Pedagogical Institute operating under the Ministry of Education, the scientific committee of the University Department of Psychiatry and the administration of the participating Mental Health Centres and schools.

Statistical Analysis

Parent-child QoL agreement was assessed using ANOVA and investigating differences between child and mother/father proxy reports for the SpLD and the control group. The

concordance of parent and child proxy–report scores was evaluated with the computation of intraclass correlation coefficients (ICC) for random effects models [25]. ICCs equal or lower to 0.40 indicate poor to fair agreement, 0.41-0.60 moderate agreement, 0.61-0.80 good agreement and over 0.80 excellent agreements. Also, agreement between parent and child proxy–report ratings was assessed by Bland-Altman 95% limits of agreement (LOA) indicating that 95% of the differences fall between these two limits [26].

Internal consistency reliability for the KINDL^{R} was determined by the calculation of Cronbach's α coefficient. Statistical significance level was set at .05 and analysis was conducted using SPSS 16.0.

Results

Regarding reliability of the KINDL ^{R} instrument, Cronbach's α coefficients exceeded the acceptable minimum of 0.7 ranging from 0.71 - 0.90 for children aged 13 years or more and 0.70 - 0.80 for children aged below 13 years.

Sociodemographic data of the two parental groups were tabulated. Regarding the SpLD group, 82% of fathers and 73% of mothers reported having high school or higher education. In the control group, percentages were 77% and 85% respectively, that is more fathers and fewer mothers were having high-higher education in the SpLD group of parents. Concerning employment, 80% of fathers and 51% of mothers in the SpLD group were fulltime employed, and 93% and 70% respectively in the control group that is more parents with typical school children (fathers and mothers) were employed. As for marital status, fewer parents with children with SpLD were still living together as couples, so 84% in the SpLD group while 92,5% in the control group reported of being married as a present status.

Regarding QoL data for SpLD child-parent dyads, Table 1 presents the mean scores of mother-child proxy reports for all dimensions of the KINDL^{R} questionnaire. Fathers are not presented due to a low number of participants in the SpLD group (n=17), since more children with SpLD were accompanied by their mothers to the diagnostic services. Significant differences were found between mother-child mean scores in the *everyday functioning in school* dimension, that is, mothers rated their child's QoL at school as being worse than that reported by children themselves. On the other hand, mothers of children with SpLD rated higher the child's *physical and emotional well-being*, assessing the child's QoL in these interrelated health dimensions better than that reported by their children.

Insert Table 1 here

In Table 2, the control group proxy mean scores are presented. The only significant mean differences in both father-child and mother-child ratings were found for the child's *physical well-being* and *self esteem* with both parents reporting QoL better in these two dimensions than children themselves.

Insert Table 2 here

Intra-class correlations and limits of agreement between mother-child and father-child proxy ratings are presented in Table 3. For the SpLD group proxy dyads, poor correlations were observed and statistically significant values were found in 3 out of 6 dimensions that is in *physical well being*, *emotional well being* and *relationship with friends* (0.32, 0.24 and 0.30 respectively).

Insert Table 3 here

For the control group of parent-child proxy dyads, agreement between father-child or mother-child ratings were significant (p=.001) in all dimensions of QoL (0.23 - 0.46), except for the *physical well-being* in father-child ratings, so agreement according

to ICCs was considered poor to fair. Similar evaluation is provided by the limits of agreement (LOA) as defined by the Bland-Altman method indicating that agreement found between the child self-report and parent-proxy report dimensions was poor.

Discussion

The present study is the first one investigating child-parent QoL agreement in children with SpLD, using proxy measurements and including control group ratings. Previous relevant studies have reported either parent or child QoL ratings independently of each other [18, 19]. So, based on recent findings, children with SpLD of 8-14 years reported poorer QoL than typically developing children, identifying deficits in *emotional well-being*, *self-esteem*, and *relationships* with *family* and *friends*, while surprisingly, the dimension of *everyday functioning in school* was not an area of their concern [19]. Considering the scarcity of relevant findings, it could be suggested that so far, children with SpLD and their parents seem to experience the presence of emotional and social deficits in the child's QoL [18, 19]. Whether children with SpLD and their parents perceive similarly or differently QoL and whether and why their methods of assessment may be divergent, it is not really known. The present study constitutes a first attempt to investigate these queries.

Regarding the SpLD results, mother-proxy differences referred to the child's *everyday functioning in school*, as it was hypothesized. Accordingly, the child's QoL in this problem-dimension was perceived by mothers as being more compromised than children themselves (Table 1). The present findings are in agreement with our earlier results [19], indicating that children with SpLD may report several QoL deficits but not including the relevant to the child's problem dimension that is *functioning in school*. So, it seems that while children with SpLD may not be so able to identify QoL deficits

regarding their school difficulties, their mothers may be more willing to do so. Such differences can be related to how children and adults experience and assess academic difficulties, employing emotional or cognitive mechanisms that are different in child and parent QoL assessments.

In this respect, several studies provide evidence on differences in child-parent QoL ratings and assessments. In mother-proxy reports, depressed children indicated better mental health than that assessed by their mothers [6]. Another similar corroborating finding indicated that adolescents with type I diabetes reported optimal well-being, which was not really expected for physically ill children [9]. The findings of the present study are in agreement with such evidence supporting the hypothesis that discrepancies would be evident in areas of QoL that are relevant to the child's problem. Thus in the present case of children with SpLD, proxy differences referred to the child's *everyday functioning in school*, a dimension stirring emotional burden for both children and their parents.

Possible interpretations may be considered as to why children with SpLD show more positive ratings for their *everyday school functioning* than their mothers. It could be argued that children with SpLD, like physically ill or depressed children, may underestimate the target problem as to protect themselves from a stressful recognition of it, or they may have adjusted to the problem and thus do not experience deficits of Qol regarding their academic functioning. Moreover, socio-cultural components may accentuate differences between child-parent QoL perceptions in specific dimensions. So, within the cultural context of this study, a high value was attached to academic achievement exerting considerable pressure on how parents and children perceive and deal with SpLD. Parents may become more anxious and overemphasize the child's difficulty in school, while children may want to bypass their problems.

Furthermore, differential QoL perceptions were observed between mothers and children with SpLD regarding *physical* and *emotional well-being* that is a difference in how they perceived and rated their child's health (Table1). So, these mothers may experience their children to be physically and emotionally healthier than how children experience themselves. One could possibly consider such assessment as a spontaneous attempt of mothers to balance felt frustrations regarding their children's failures in academic achievement, perhaps making an overstatement about the child's physical and psychological well being.

Regarding the control group, a higher degree of converging QoL perceptions was evident in parent-proxy dyads, showing several similarities in both mother-child and father-child reports than those in the respective SpLD mother-proxy dyads (Table 2). So, mothers and fathers of typically developing children seemed more prone to converge with their children's QoL perceptions regarding the child's *emotional well-being, relationship with family, friends* and *school functioning.* Differences were observed in two QoL domains as both parents rated higher their children's *physical well being* and *self-esteem.* This finding is in line with evidence provided by Theunissen et al.[27] and the review of Upton et al.[2], who reported that parents of typical children tend to overestimate the child's QoL.

A possible explanation for parent-child proxy differences regarding the child's *physical well being* may concern the adult ability of making judgments based on a variety of health indicators, while children consider concrete and recent experiences, for example a child rating low on health because of having a stomach ache in the last week [17], an observation that was valid for the present study as well.

In addition, it could be argued that parents tend to view their children through their own expectations or concerns. So parents of healthy children may experience high

expectations from their children, rating higher their child's *well being* and *self-esteem*, that is an indication of trusting the child to cope with school, or a reflection of their own well-being.

Regarding associations of parent-proxy ratings, the correlations performed reflected some degree of similarities between children and parents in the direction of their ratings (Tables 3). So, while parent-child ratings may follow similar patterns in certain QoL dimensions, the level of values assigned by the two parties may differ (tables 1 and 2, -see differences of means and findings of ANOVA).

Concerning correlations and ICC outcomes in the SpLD child-mother dyads, the dimensions showing some similar assessment tendencies referred to the child's *physical*, *emotional* and *social well being* while they seem to employ different patterns of Qol in the dimension of *self-esteem* and *family relations.* These results are in line with other findings, e.g. Bastiaansen et al. [10] and Kiss et al. [6] concerning agreement in children with psychiatric disorders and for depressed children.

It can be hypothesized that dimensions of *self-esteem* and *family relations* may reflect emotional difficulties for both children and parents and could probably explain differences in their assessments.

Regarding typical child-mother or child-father dyads, correlations were found in all dimensions of QoL assessed (Table 3). These associations are consistent with other findings as of Robitail et al. [4], a study where the ICC coefficients were moderate for typical children of 7 European countries in the majority of QoL dimensions (*physical well-being, self perception, peers and social support, school environment and financial resources*), and also consistent with the findings of Theunissen et al. [27].

In overall, both parents of typical children seem to share a high level of common QoL assessment patterns with their children and between themselves, while mothers of children with SpLD seem to have more within differences.

Conclusion

While SpLD is not a major disability that could cause controversial QoL assessments, a certain degree of differences in proxy ratings were found, with mothers either underestimating or overestimating certain dimensions. Analysis thus of SpLD proxy dyads provided some agreement evidence while agreement was more evident in the control group dyads.

Differences between children with SpLD and their mothers may reflect lack of communication regarding the target problem and the consequences in inner and social life. SpLD may become a serious issue for the child's self esteem and his/her emotional and social well-being. Taking into consideration QoL findings regarding families with children with SpLD, action plans can be developed by mental health professionals and educators to equip parents with skills to cope with their children's emotional experiences and be able to support them in how to deal with negative feelings and stressful events in their daily school functioning.

Limitations

The sample of this study was composed by children with SpLD and their parents recruited in two Mental Health Centers and by a control group as a convenience sample of typically developing children and parents recruited in schools located in the same area. These cohorts however cannot be considered representative samples of these populations. For example the education level of parents participating in the study was relatively high, limiting generalizability of the findings. Replication of the study with larger samples,

application of criteria of representativeness could provide more assurance for the findings.

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Table 1. Child with SpLD and mother-proxy KINDL^R mean difference scores and SD (ANOVA)

KINDL^R	Children N=99 Mean SD	Mothers N=99 Mean SD	Mean Difference (95% CI)	f	p
Physical well-being	75.65 14.77	84.54 14.44	8.89 (-12.27 , -5.5)	18.323	.000*
Emotional well-being	76.78 15.44	80.90 13.76	4.12 (-7.72 , -0.53)	3.935	.049*
Self-esteem	64.64 18.28	66.31 13.31	1.67 (-10.8 , -2.23)	.537	.464
Family	74.84 16.23	74.69 12.55	-0.15 (-5.12 , 1.99)	.005	.942
Friends	79.29 15.76	80.45 12.69	1.16 (-4.54 , 2.22)	.326	.569
School	66.06 14.41	57.69 13.81	-8.37 (5.03 , 12.51)	17.369	.000*

* $p < 0.05$

Table 2. Typical child and father / mother proxy KINDL^R mean difference scores and SD (ANOVA)

KINDL^R	Children N=217 Mean SD	Fathers N=217 Mean SD	Mean Difference (95% CI)	f	p	Children N=282 Mean SD	Mothers N=282 Mean SD	Mean Difference (95% CI)	f	p
Physical well-being	81.75 13.29	84.95 12.60	3.2 (1.43 , 4.97)	6.633	.01*	81.42 13.21	84.13 12.35	2.71 (0.59 . 4.83)	6.342	.012*
Emotional well-being	83.96 12.27	85.55 11.23	1.59 (-0.29 , 3.47)	1.980	.16	83.56 12.63	85.12 11.72	1.56 (0.46 . 3.58)	2.311	.129
Self-esteem	68.77 17.10	73.50 13.94	4.73 (1.79 , 7.67)	9.942	.002*	69.21 17.16	74.09 13.81	4.89 (2.30 . 7.46)	13.850	.000*
Family	82.07 13.12	80.82 12.25	-1.25 (-3.64 , 1.14)	1.042	.308	82.09 13.47	80.17 12.39	-1.92 (-4.06 . 0.22)	3.103	.079
Friends	84.53 13.48	82.69 10.44	-1.84 (-4.11 , 0.43)	2.534	.112	84.84 13.86	83.54 11.35	-1.3 (-3.39 . 0.78)	1.471	.226
School	72.05 15.82	73.75 13.51	1.7 (-1.08 , 4.78)	1.457	.228	72.83 15.67	74.64 14.66	1.81 (-0.70 . 4.32)	2.002	.158

*p < .05

Table 3. Agreement between child-father and child-mother KINDL ^{R} scores in SpLD and typical parent-child dyads

Dimensions of KINDL^{R}	Fathers (N=217)		Mothers (N=381)			
	Typical dyads (N=217)		SpLD dyads (N=99)		Typical dyads (N=282)	
	ICC	LOA	ICC	LOA	ICC	LOA
Physical well-being	0.46***	-23.27; 29.67	0.22***	-25.05; 42.83	0.24***	-28.57; 33.81
Emotional well-being	0.28***	-26.54; 29.72	0.22**	-31.90; 41.15	0.31***	-26.98; 30.09
Self-esteem	0.27***	-32.38; 41.82	0.06	-42.15; 45.48	0.32***	-30.58; 40.35
Family	0.31***	-31.03; 28.54	0.13	-38.65; 38.35	0.23***	-34.00; 30.16
Friends	0.25***	-31.22; 27.54	0.30**	-32.73; 35.05	0.33***	-30.57; 27.98
School	0.27***	-33.83; 37.24	0.12	-43.81; 27.09	0.27***	-34.69; 38.30

***p<.001, **p<.01,
95% limits of agreement (LOA) as defined by Bland-Altman method.